

Congress of the United States
Washington, DC 20515

March 13, 2023

The Honorable Xavier Becerra
Secretary
U.S. Department of Health & Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

RE: Notice for Advancing Health Equity for Intersex Individuals

Dear Secretary Becerra,

As members of the U.S. House of Representatives, we strongly support the Administration's efforts to publish a report on "Promising Practices for Advancing Health Equity for Intersex Individuals." Intersex people—those born with variations in their physical sex characteristics—are a substantial and important part of the U.S. population and of the LGBTQI+ population, but for too long their needs have gone unaddressed due to silence, stigma, and lack of education. Given the many challenges intersex populations face—including the frequency of forced, harmful surgeries on intersex children, as well as other forms of discrimination and gaps in care and supports—this report will be an important step forward in ensuring health equity for this vulnerable population.

Current Clinical, Research, and Policy Gaps:

Despite estimates that approximately 1.7% of the population is born with intersex traits,¹ no major federal surveys or programs collect usable data on intersex populations. A growing body of data from non-federal and international sources paints an alarming picture. A 2020 report by the National Academies of Sciences, Engineering, and Medicine found evidence of intersex health disparities in areas including cardiovascular, sexual, and reproductive health, and stated that: "[i]ntersex health disparities appear to be driven in large part by the medical approach to intersex traits, which has been informed by the same stigmas experienced by [other sexual and gender minority] populations."² A 2018 national study of intersex adults found that 53% of respondents reported "fair" or "poor" mental health, and more than 43% had poor physical health (compared to 17.7% of the general population).³ Among intersex people who also self-identify as sexual minorities or transgender, one survey found nine in 10 reported some level of poor physical health—a much higher rate than non-intersex sexual minority and transgender respondents.⁴ Individuals with intersex traits have a difficult time accessing healthcare due to

¹ Melanie Blackless et al, *How Sexually Dimorphic Are We? Review and Synthesis*, American Journal of Human Biology 12:151-166 (2000).

² National Academies of Sciences, Engineering, and Medicine, *Understanding the Well-Being of LGBTQI+ Populations*, the National Academies Press (2020), <https://doi.org/10.17226/25877>.

³ Rosenwohl-Mack et. al, *A national study on the physical and mental health of intersex adults in the U.S.*, PONE, (2020), <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0240088>.

⁴ Caroline Medina and Lindsay Mahowald, *Key Issues Facing People With Intersex Traits*, Center for American Progress (October 26, 2021), <https://www.americanprogress.org/article/key-issues-facing-people-intersex-traits/>.

cost and fear of discrimination.⁵ Intersex people are more likely than the general public to report negative experiences when accessing healthcare.⁶ For example, 59% of respondents to a 2022 survey reported hearing harsh and abusive language by medical providers because of their intersex traits, and 58% reported providers looking and feeling physically uncomfortable treating them.⁷ The discrimination and stigmatization that intersex people experience takes a toll; a 2021 study found that 48% of intersex youth seriously considered suicide in the prior year.⁸ Studies from other nations around the world have similarly found evidence of health disparities, as well as educational and economic disparities and widespread experiences of discrimination.⁹

The Biden Administration has taken important strides to include the intersex community within its larger LGBTQI+ equity efforts, and the Department's report should reflect this as well. This intersex-inclusive approach is reflected in the express directives of President Biden's Executive Order 14075; in the recent landmark reports on LGBTQI+ health and data collection from the National Academies of Sciences, Engineering, and Medicine;¹⁰ and in some key HHS initiatives to date, such as the National Institute of Health's Sexual and Gender Minority Research Office (SGMRO) and SGM research efforts, and HHS's recent proposed rule recognizing that discrimination based on sexual orientation, gender identity, and sex characteristics (including intersex traits) are all prohibited forms of sex discrimination. The forthcoming report should build on and strengthen this inclusive approach by providing a roadmap for incorporating intersex health equity into efforts to advance health, gender, and LGBTQI+ equity.

Critically, this landmark report should address one of the biggest health challenges that impacts the intersex community: coercive and medically unnecessary surgeries on intersex infants and children. Such surgeries are most often performed before the age of two—many years before a child with an intersex variation will have any ability to assess how potential medical interventions might align with or undermine their own medical needs, embodiment priorities, and reproductive and sexual autonomy in adulthood, and thus to provide informed assent or consent. Unlike other childhood medical procedures, these surgeries on intersex children are not compelled by any clear medical need, yet they are associated with risks of serious harm; they have high complication rates and long-term consequences such as infertility and reduced sexual function, among other impacts.¹¹ This is a reproductive justice issue, as the

⁵ *Id.*

⁶ Zeeman et. al, *A Systematic Review of the Health and Healthcare Inequalities for People with Intersex Variance*, International Journal of Environmental Research and Public Health 3 (2020), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7559554/pdf/ijerph-17-06533.pdf>

⁷ Medina et. al, *Discrimination and Barriers to Well-Being: The State of the LGBTQI+ Community in 2022*, Center for American Progress, (2023), <https://www.americanprogress.org/article/discrimination-and-barriers-to-well-being-the-state-of-the-lgbtqi-community-in-2022/>

⁸ *The Mental Health and Well-being of LGBTQ Youth who are Intersex*, The Trevor Project 3 (2021), <https://www.thetrevorproject.org/wp-content/uploads/2021/12/Intersex-Youth-Mental-Health-Report.pdf>

⁹ European Union Fundamental Rights Agency, *EU-LGBTI II: A long way to go for LGBTI equality* (2020); de Vries, A.L.C., et al., Mental health of a large group of adults with disorders of sex development in six European countries. 81 Psychosomatic Med. 629–640 (2019); Jones T., *The needs of students with intersex variations*, 16 SEX EDUC. 602 (2016).

¹⁰ See, e.g., Charlotte J. Patterson et. al, *Understanding the Well-Being of LGBTQI+ Populations*, National Academies of Sciences, Engineering, and Medicine (2020), <https://doi.org/10.17226/25877>.

¹¹ Medina and Mahowald, *supra* n. 3.

removal of internal sex organs at a young age robs intersex people of their bodily and reproductive autonomy. These practices also raise serious questions under existing U.S. laws regarding informed consent, bodily autonomy, and civil rights. Numerous U.S. legal and medical organizations, including the American Academy of Family Physicians,¹² American Bar Association,¹³ and GLMA: Health Professionals Advancing LGBTQ Equality,¹⁴ oppose performing these surgeries in the absence of either informed decision-making by the patient themselves or an urgent medical need that would justify operating on the basis of proxy consent. These practices are increasingly recognized as a human rights violation by international treaty bodies,¹⁵ and have been similarly and repeatedly denounced by the United States on the global stage.¹⁶

The government must do more to address these harmful practices. The Biden Administration has taken important steps to protect LGBTQI+ youth from related harms such as conversion therapy practices, which intersex youth are also especially likely to experience.¹⁷ Much like how efforts to change someone's gender identity or sexual orientation are often rooted in a binary notion of "normality" based on strict and binary views of gender, imposing surgeries on intersex youth to change their physical sex characteristics is an attempt to enforce compliance with binary and traditional expectations of what people's bodies should look like. Like conversion therapy practices, these early intersex surgeries do not treat any present condition that threatens the patient's health and cannot be justified by current medical science. The Administration should detail a whole-of-government approach to ending these forced surgeries both in the United States and around the world, just as it is doing to address conversion therapy. This approach should include ensuring federal funds are not used for these harmful practices; reviewing the practices of hospitals known to engage in potentially harmful practices; and disseminating educational resources for families, as well as training and technical assistance for health care providers.

The report should also address the need to include accurate, inclusive information about diversity in sex characteristics and sex development in health, biology, and medical education. Despite variations in sex characteristics being a natural part of human diversity, young people with these variations, as well as their peers, typically receive biology and health education that

¹² *Genital Surgeries in Intersex Children*, American Academy of Family Physicians (2018), <https://www.aafp.org/about/policies/all/genital-surgeries.html>.

¹³ *Resolution 511*, American Bar Association (2023), https://www.americanbar.org/news/reporter_resources/midyear-meeting-2023/house-of-delegates-resolutions/511/.

¹⁴ *GLMA Adopts Resolution on Care for Children with DSD*, GLMA, <https://www.glma.org/index.cfm?fuseaction=Feature.showFeature&CategoryID=1&FeatureID=796>.

¹⁵ See, e.g., Women's Human Rights and Gender Section of the Office of the United Nations High Commissioner for Human Rights (OHCHR), *Human Rights Violations Against Intersex People* <https://www.ohchr.org/sites/default/files/Documents/Issues/Discrimination/LGBT/BackgroundNoteHumanRightsViolationsagainstIntersexPeople.pdf>.

¹⁶ Remarks of Secretary Antony J. Blinken At the United Nations LGBTI Core Group Event (Sept. 19, 2022), <https://www.state.gov/secretary-antony-j-blinken-at-the-united-nations-lgbti-core-group-event/>; United Nations Human Rights Council 48th session Joint Statement on the Human Rights of Intersex Persons (Oct. 4, 2021), <https://www.bmeia.gv.at/oev-genf/speeches/alle/2021/10/united-nations-human-rights-council-48th-session-joint-statement-on-the-human-rights-of-intersex-persons/>.

¹⁷ *The Mental Health and Well-being of LGBTQ Youth who are Intersex*, The Trevor Project (2021), <https://www.thetrevorproject.org/wp-content/uploads/2021/12/Intersex-Youth-Mental-Health-Report.pdf>.

does not acknowledge that bodies like theirs can even exist. Even health care professionals typically do not receive even the most basic information about intersex variations, let alone instruction on providing clinically and culturally appropriate care to intersex patients. Ensuring information on diversity in sex characteristics and sex development is integrated into health, biology, and medical education will help ease harmful stigma, increase understanding, and empower providers and patients to take an active role in improving care.

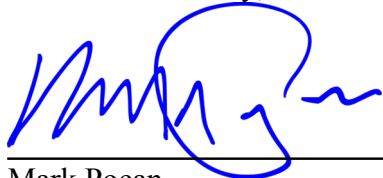
The report should additionally address how recent bills and laws restricting the rights of transgender people with respect to health care, education, and other areas also negatively impact the health and wellbeing of the intersex community. For example, nearly all bills restricting access to gender-affirming care include specific exceptions to allow coercive and medically unnecessary surgeries on intersex infants and children.

Lastly, given the existing evidence of health and social disparities affecting intersex populations, federal data collection is needed to better understand these challenges and inform solutions. We applaud President Biden's directive to federal agencies in Executive Order 14075 to "advance the responsible and effective collection and use of data on sexual orientation, gender identity, and sex characteristics." Building on this directive and the Biden Administration's recent Federal Evidence Agenda on Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Equity, HHS and other federal agencies should include in their forthcoming data action plans specific steps to test and add sex characteristics measures to key federal surveys. For example, HHS should add these measures to CDC's National Health Interview Survey (NHIS) and Behavioral Risk Factor Surveillance System (BRFSS), and SAMHSA's National Survey of Drug Use and Health (NSDUH). This is a priority for members of Congress, which is why last Congress, the House of Representatives passed H.R. 4176, the LGBTQI+ Data Inclusion Act, to require federal data collection of voluntary, self-disclosed information on variations in sex characteristics, as well as sexual orientation and gender identity. We firmly believe the collection of voluntary data on the intersex community is essential to informing strategies to best address their healthcare needs and urge your upcoming report to highlight this as well.


Conclusion

As members of Congress, we are committed to addressing these and other challenges the intersex community faces. We welcome the Department's upcoming report, and we look forward to working with you to advance health equity for the intersex community.

Sincerely,



Mark Pocan
Member of Congress



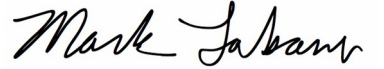
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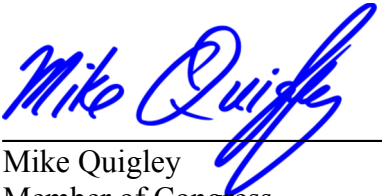
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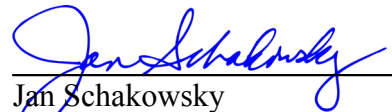
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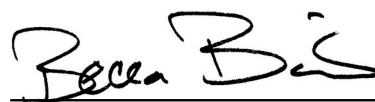
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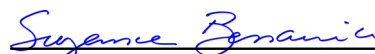
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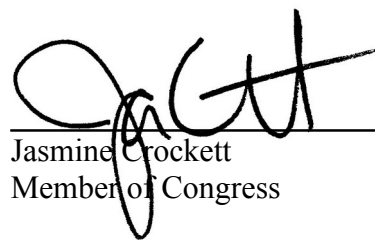
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